Not Just Once

The Bimonthly Newsletter of CMS' National Medicare Mammography Campaign

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WELCOME!

This issue includes news from the Institute of Medicine (page 2), an article about cultural barriers to mammography (page 4) and a report about an educational campaign in Washington, D.C. (page 7).

Coming in September-October: an update on the activities of the Centers for Medicare & Medicaid Services (CMS) National Medicare Mammography Campaign. We are developing new partnerships with two federal agencies – the Centers for Disease Control and Prevention (CDC), and the Office on Women's Health (OWH). The Campaign will support distribution of a new CDC mammography educational brochure. CMS and the Regional Mammography Coordinators will be working with OWH and its regional Centers of Excellence in Women's Health. In addition, we continue to work with the National Cancer Institute.

Not Just Once focuses on the work of the Medicare Mammography Campaign, contractors, and other partners. As always, we encourage YOU to submit ideas or stories. Please send these to Editor Maribeth Fonner at **maribeth.fonner@cms.hhs.gov** at or phone her at (816) 426-6349.

Sincerely,

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In this Issue

Increased Access to High-Quality Mammography Needed to Reduce Cancer Deaths

Shortage of Screening Specialists Should Be Addressed to Deal With Capacity Crisis

June 10, 2004 – WASHINGTON – While new technologies hold promise for increasing the accuracy of breast cancer detection, improving access to mammography and broadening the pool of medical personnel who can interpret mammograms offer the greatest potential for immediately reducing the number of lives lost to breast cancer in the United States, says a new report from the Institute of Medicine and National Research Council of the National Academies.

"There is a suite of new devices under evaluation -- such as ultrasound and computer-aided detection (CAD) -- that should make early detection even more effective in the future, although improvements in the next few years are likely to be incremental rather than revolutionary," said committee chair Edward Penhoet, director of science and higher education programs, Gordon and Betty Moore Foundation, San Francisco, and former dean, School of Public Health, University of California, Berkeley.

New technologies based on protein or gene profiling hold promise for providing more personalized screenings and identifying women at greatest risk for breast cancer. However, it remains to be shown whether these technologies will yield results that are reliable enough to be useful in the early detection of breast cancer, said the committee that wrote the report. "In the meantime, because current mammography technology is good but imperfect, and because there are many barriers hindering access to mammography, too many women will die from breast cancer this year," Penhoet said. "Improving and increasing the use of current mammography technology is the most effective strategy we have right now for further reducing the toll of breast cancer."

More than 200,000 new cases of breast cancer will be diagnosed this year, and more than 40,000 women will die from the disease. One of the biggest problems facing women today is that their access to breast cancer screening is endangered due to a shortage of breast imaging specialists, the report says. Each year, more than 1.2 million American women turn 40, the age when most are recommended to get their first mammogram, but there are not enough breast imaging specialists to keep up with the demand. Fewer radiologists are going into breast imaging because of heavy regulation, fear of lawsuits, and low reimbursement for long hours. At the same time, mammography facilities are closing faster than new ones are opening. Between 2000 and 2003, the number of mammography facilities operating in the United States has dropped from 9,400 to 8,600 -- an 8.5 percent decrease. As a result, women are being made to wait up to five months for mammograms in some areas, the report notes.

Studies in the United Kingdom show that trained nonphysician health care professionals can interpret results with the same accuracy and speed as radiologists. Given the failure of the U.S. health care system to keep pace with the growing demand for mammography, the committee recommended that mammography facilities should enlist specially trained nonphysician personnel to pre-screen or double-read mammograms to expand screening facilities' capacity. Nonphysician personnel would not make diagnoses, and every mammogram would be independently viewed by a breast imaging specialist.

To improve the quality of cancer screening, the United States should adopt elements of screening programs that have proved successful in Sweden, the Netherlands, and the United Kingdom, which have lower rates of false-positive results, the committee said. It estimated that reducing the number of false positives could cut the costs related to additional testing by $100 million a year because approximately 200,000 fewer women would be called back for follow-up work. The United States also should consider such practices as requiring double readings of mammograms, interpretation of mammograms in high-volume centers, and screening services that also integrate treatment, counseling, and other support services.

Tests are under way to assess the clinical value of ways to refine screening strategies for high-risk women and to improve the accuracy

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of mammographic interpretations. These methods include digital mammography, CAD, ultrasound, and magnetic resonance imaging. The committee encourages the validation and integration of new technologies into breast cancer screening because current mammography is imperfect and does not work equally well in all women. Mammography correctly flags undetected cancers 83 percent to 95 percent of the time, but this means that up to 17 percent of tumors go undetected. Moreover, the chance of a false-positive result from a traditional mammogram is about 1 in 10.

The report notes that research and discovery phases of new technology development are proceeding well. The weak link in development is the phase in which technologies are shown to improve health outcomes and that they can be used effectively in routine clinical practice. Many cancer detection technologies that have been proposed and developed over the years have proved to be of no value to patients or medical practice, the committee noted. It urged that more attention be paid to validating technologies and building a more robust system for assessing whether they will be useful in clinical practice. Organizations that fund breast cancer research, such as the National Institutes of Health, Department of Defense, and private foundations, should support research on how best to evaluate and apply new screening and detection technologies.

Because there is so much individual variation in susceptibility to breast cancer, more refined screening strategies should be developed, the report says. Screening based on individualized genetic risk profiles for women will substantially improve early detection efforts, the report says. However, more research is needed on genetic risk factors before these biologically based technologies can be used fully to tailor detection strategies.

In addition, the actual risks of developing breast cancer need to be better communicated to women so that they can make informed decisions about screening and their lifestyle. Surveys show that older women are more likely to underestimate their risk than younger women, and that younger women tend to overestimate their risk. The National Cancer Institute, private foundations, and others should develop better tools for communicating risk to help health care providers discuss breast cancer risk more effectively with patients and the media.

The new report, **Saving Women's Lives: Strategies for Improving the Early Detection and Diagnosis of Breast Cancer,** expands on the work of a previous IOM and NRC committee that a few years ago examined the array of promising detection and diagnostic technologies under development. That committee's report, **Mammography and Beyond: Developing Technologies for Early Detection of Breast Cancer,** published in 2001, concluded that mammography -- despite its problems -- was still the best choice for screening the general population to detect breast cancer at early and treatable stages.

The new report was sponsored by the Breast Cancer Research Foundation, National Cancer Institute, Apex Foundation, Josiah H. Macy Jr. Kansas Health Foundation, Carl J. Herzog Foundation, Mr. Corbin Gwaltney, and Mr. John Castle. The Institute of Medicine and the National Research Council are private, nonprofit institutions that provide science and health policy advice under a congressional charter.

Pre-publication copies of **Saving Women's Lives: Strategies for Improving the Early Detection and Diagnosis of Breast Cancer** are available from the National Academies Press; tel. 202-334-3313 or 1-800-624-6242 or on the Internet at **www.nap.edu**. The cost of the report is $51.95 (prepaid) plus shipping charges of $4.50 for the first copy and $.95 for each additional copy.

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*More information about the report is available on the web at **http://books.nap.edu/catalog/11016.html***

Cultural and Communication Factors in Mammography

-Fabio Sabogal, PhD and Mary Giammona, MD, MPH

As the U.S. population becomes increasingly multicultural, the role of cultural factors to enhance preventive care is getting more attention. Research has showed that ethnically diverse and older women are the least likely group to obtain mammograms and return for rescreening.[1] Healthcare providers' cultural competency and patients' cultural beliefs may be associated with mammography screening compliance and patient satisfaction.

Culturally competent healthcare providers explore in a sensitive manner a patient's health beliefs, attitudes, and any cultural barriers to obtaining needed care. Physician-patient discussion of breast cancer screening is one of the most important predictors for obtaining initial and regular mammograms.[2] Even a simple and brief conversation is effective. However, partly due to cultural factors, patients might be afraid or embarrassed to talk about breast care. Providers can learn to reinforce positive cultural values and recognize cultural beliefs that may encourage initial and repeated breast cancer screening.

Below is a description of some of the common cultural implications for various racial and ethnic groups. While this is not meant to be an exhaustive list, the cultural factors detailed here can help providers better understand various barriers to mammography.

Cultural Factors – Hispanic

Modesty, fear, embarrassment and lack of preventive self-care focus have been obstacles for mammography screening and rescreening among Hispanic women.[3] For example, just 39.7 percent of California's Medicare fee-for-service Hispanic women ages 65 and older had a biennial mammogram during 2001-2002, compared to 54.0 percent of Caucasian women. "Fatalistic" and negative attitudes toward healthcare providers have also been found to be obstacles for this group.[3] About one-third of Hispanics report having problems communicating with their providers and feel their they are treated disrespectfully by them.[4]

There is great diversity among and within the various Hispanic subgroups. Hispanics belong to all races including White, Black, Asian, and Native American. But in general, healthcare providers should consider that many Hispanic women rely primarily on their family, media (e.g., radio), and healthcare professionals for health information. Hispanic women's individual needs are sometimes delayed to take care of family responsibilities and the needs of the other family members. Clinicians need to clearly communicate the importance of taking personal time for obtaining a mammogram and returning for rescreening.

Hispanic women highly value clinicians who demonstrate a caring attitude and who emphasize the health benefits of mammography screening for the health of the entire family. In addition, because Hispanic women tend to make decisions collectively, physicians should let members participate in discussions about breast cancer detection and treatment.[3]

Cultural Factors – African-American

Several breast cancer screening barriers have been identified among African-American seniors, including mistrust of the healthcare system, perceived discrimination, fear, pain, and lack of accessibility and availability of preventive services. Certain religious beliefs and fatalistic attitudes may lead to low screening rates, lack of follow-up, and disregard of treatment recommendations among African-Americans. Past negative experiences with the healthcare system and distrust of healthcare providers may cause delays in obtaining mammography screening.[5] For example, California's African-American women ages 65 and older enrolled in Medicare fee-for-service had a low biennial mammography rate of 38.5 percent during 2001-2002.

Clinicians may want to build trust, encourage women to discuss mammography concerns, and provide referral for mammography services. Family and faith-based networks may be helpful in disseminating information about breast cancer screening and referral services to this group. African American women with breast cancer and culturally competent peer-educators may also be valuable resources in mammography screening outreach activities.[5]

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Cultural Factors – Asian/Pacific Islander (API)

Modesty and embarrassment may be barriers to breast cancer screening in API communities. Cancer myths, (e.g., "cancer is contagious"), misinformation (e.g., "API women don't get breast cancer"), and negative attitudes (e.g., "cancer is a death sentence") are common, as well as a general lack of awareness of the benefits of early breast cancer detection among older API women. Literacy and English language proficiency especially are major barriers to healthcare for API women.

There is great diversity among the ethnic subgroups of API women. Major structural, linguistic, cultural, and access barriers for breast cancer screening exist. The biennial mammography rate among California's API women ages 65 and older enrolled in Medicare fee-for-service is the lowest of any group in the state at 36.7 percent from 2001-2002.

Practitioners that work with API women may dispel cancer myths, address access barriers, and be sensitive to the concerns of women with traditional beliefs. Familiar small groups, educational presentations, and interpersonal communication are essential to personalize breast cancer screening messages in API communities. Personal testimonials and real stories of API breast cancer survivors are also key to promoting positive attitudes about breast cancer screening.

Cultural Factors – Native American Indian

Most native languages do not include a word for "cancer." For the few languages that do have a translation for cancer, the meanings are "the disease for which there is no cure" or "the disease that eats the body."[6] There are 217 native languages spoken in the U.S and 400 federally recognized tribes; for some older native people, English may be a second language or not spoken at all. Native American Indian women ages 65 and older enrolled in Medicare fee-for-service in California had low biennial mammography rates of 47.6 percent during 2001-2002.

Many native cultures believe that diseases such as cancer should not be discussed because such communication invites the disease into the body. Some Native American Indians believe that a cancer diagnosis is synonymous with a death sentence.[6] Many older Native American Indians prefer traditional medicine, and sickness and death are perceived differently.

Clinicians may want to use a storytelling communication style since many native women may not communicate in a business "linear" manner. When discussing breast cancer with Native American Indian women, healthcare providers need to understand that trust is a major issue, and disclosure of information to a stranger may be given only after trust is established. Also, few breast health educational materials for Native Americans are available. There is a need to develop culturally appropriate resources for this community.

Cultural Factors – General

In ethnically diverse groups, women are often in charge of the healthcare of the entire family, and opinions of other family members can be very important. Trust in lay healers and non-clinical treatments are common. Distrust regarding healthcare and government, even fear of deportation, may cause ethnically diverse women to delay medical care, seeking healthcare only when a crisis occurs.

Falsely low perceptions of breast cancer risk may also permeate ethnically diverse groups, specifically the false notion that a woman is not at risk if she is post-menopausal. Talking openly about breast health topics usually is not common, and thus is a discussion area that needs to be broached sensitively by healthcare providers.

Members of ethnically diverse groups may also be driven by a belief that disease is determined by outside forces. In some cultures, an offended spirit or punishment for a sin is thought to be the cause of illness. Therefore, breast cancer may be associated with strong fears, hopelessness, and stoic or fatalistic attitudes that lead people to accept that "whatever will be will be" and that pain must be endured.

Respectful physician-patient interactions are tantamount in mammography screening—with sensitivity healthcare providers can help women of all ethnic backgrounds feel comfortable talking about regular breast cancer screening.

In summary, taking the time to build trust, having a caring attitude and conveying respect while talking

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about the benefits of mammography screening are associated with better breast cancer screening outcomes and patient satisfaction. Regardless of cultural factors, physicians' enthusiasm about breast health is critical when communicating with ethnically diverse women. Women who perceive their physicians to be enthusiastic about mammography are four and a half times more likely to have had a mammogram than women whose physicians have little or no enthusiasm when discussing the procedure.[7]

Dr. Sabogal is a Senior Health Care Information Specialist and Dr. Giammona is the Medical Director at Lumetra, the Quality Improvement Organization in San Francisco, CA.

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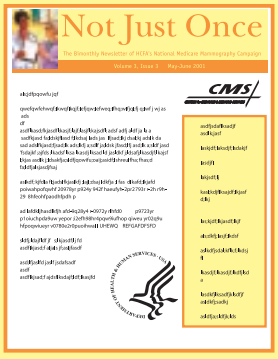
To read back issues of the ***Not Just Once*** Newsletter, please visit the website: **www.cms.hhs.gov/preventiveservices/1a.asp**



Delmarva Foundation Uses Study on the Disparity in Mammography Rates to Launch Campaign in D.C.

-Robin L. Wolfgang, MA

When Delmarva Foundation, the Quality Improvement Organization for the District of Columbia, analyzed data about women with Medicare, it discovered that elderly and disabled women are less likely to have routine mammograms if they are African-American or live in some of the city's less affluent Wards. In early May, Delmarva distributed a study that showed that only 51 percent of black women ages 50-67 living in the District had a mammogram in 2001 or 2002, compared with 62 percent of their white counterparts. Women living in the city's wealthiest section or Ward 3 had the highest rate of women who had a mammogram in that period, 66 percent, and was the only Ward of 8 Wards in the District to do better than the 60 percent national average. The city's overall rate was a 53 percent. Armed with this data, Delmarva set out to educate the media, community, providers and beneficiaries.

Delmarva began pitching the study and release to reporters for a week prior to the embargoed May 19, 2004 release date. The Associated Press (AP) wrote a piece and The Washington Post did a story on the front page of the Metro section including quotes from Deneen Richmond, the Executive Director of Delmarva's district office. A Washington Post affiliate publication designed for transit commuters published the AP story with a teaser on the front page. Delmarva also wrote a "Letter to the Editor" of The Washington Post. In addition to print coverage, Delmarva pre-taped interviews with news radio station WTOP and National Public Radio affiliate WAMU. To reach the African-American audience, Delmarva taped a half hour show on WPGC, an urban radio station with a sister gospel station. This show aired on both stations on Saturday and Sunday morning. Ms. Richmond also had interviews with News Channel 8, the 24-hour cable news channel and WJLA, the local ABC Affiliate, as well as a taping for "Viewpoint," an NBC show. The other two television stations read the information on their morning and evening news.

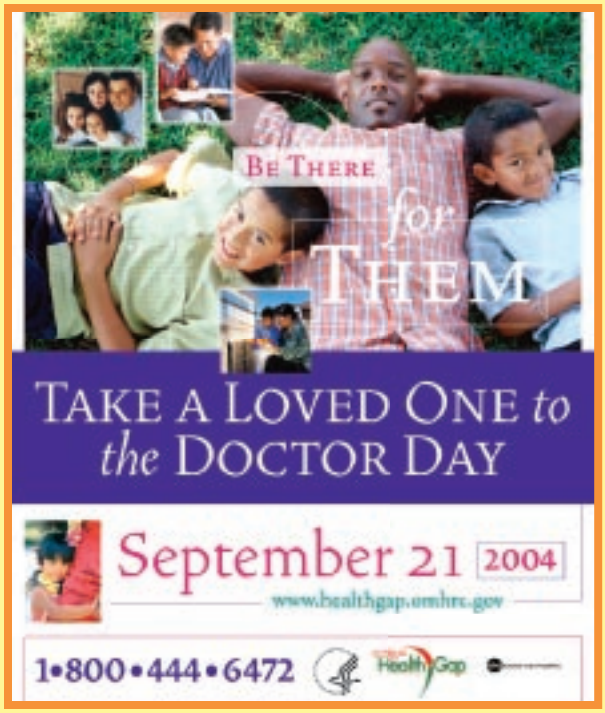
What peaked the media's interest in this story was the true local nature of the data provided. The media consistently highlighted that the mortality rate for breast cancer in the District is higher than in any other state in the nation. Also featured was that some neighborhoods have few or no health care providers offering mammograms. The media success led to the next phase of the campaign which included utilizing community partners like faith-based organizations and beauty parlors to disseminate information prepared by Delmarva about the need to test for breast cancer yearly and the coverage provided by Medicare. Delmarva also worked to educate mammography centers and physicians with offices in the low performing zip codes.

The final phase of the campaign was a social marketing promotion throughout the month of June where three call to action self-mailers were sent to beneficiaries in the target areas every other week. This repetitive mailing of a tested message was designed via focus groups and includes a perforated section for a woman to record her appointment date, time and location and to bring with her to a doctor's appointment. Mammography centers will then collect these cards and send them to Delmarva to be tracked.

For copies of campaign materials or to learn more about how the campaign was developed, visit **www.delmarvafoundation.org** or contact the Delmarva Foundation Communications Department at (410) 822-0697.

Ms. Wolfgang is the Director of Corporate Communications with Delmarva Foundation, the Quality Improvement Organization in Washington, DC and Easton, MD.

Take a Loved One to the Doctor Day is September 21, 2004



Take A Loved One to the Doctor Day, the third Tuesday of September, is a key element of the "Closing the Health Gap" Campaign. The focus of the day is to encourage individuals to take charge of their health by visiting a health professional (such as a doctor or nurse), making an appointment for a visit, attending a health event in the community, or helping a friend, neighbor or family member do the same. The Department of Health & Human Services (HHS) and its partners also encourage communities around the country to organize health events on this day. In 2004, *Take a Loved One to the Doctor Day* is September 21.

The partnerships being created among HHS and many national and local organizations aim to inform and educate communities of color about the health gap, empower individuals to adopt healthier lifestyles, and obtain access to health care. Closing the Health Gap supports HHS' efforts to eliminate racial and ethnic health disparities and the goals of Healthy People 2010, the nation's agenda for improving the public health. It also advances the HHS Steps to a Healthier U.S. program and the President's Healthier U.S. Initiative, which aim to provide the public with the health information needed to live healthier lives.

Many organizations and communities are sponsoring health events on September 21. Some communities will have health events or screenings; others will have health centers ready to take new patients on that day.

For more information about *Take A Loved One to the Doctor Day* and how you can be involved, visit **www.healthgap.omhrc.gov/2004drday.htm** or phone 1-800-444-6472.

This story was adapted from the "About Take A Loved One to the Doctor Day" webpage, ***www.healthgap.omhrc.gov/learnmore.htm***

CMS's Regional Mammography Coordinators

CMS's Regional Mammography Coordinators are a wonderful resource for partners working on breast cancer projects focusing on older women. We encourage you to make contact with our coordinators listed below and learn more about how we can be of assistance to you.

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Mammograms… Not Just Once, But for a Lifetime Large-print, easy to read brochure that defines mammography, describes who needs to be screened, and Medicare Information. (maximum order 5000)	English Spanish	H496 H497	8.5 x 11	
Mammograms for Older Women Poster Includes slogan with Medicare information. A poster featuring an older woman, available for display in health care settings. (minimum order: 20, maximum 5000)	English Spanish	G500 G501	11 x 17	
Mammograms for Older Women Bookmark Includes slogan with medicare information. Bookmark features an older woman with facts in breast cancer, mammography, and Medicare coverage. (maximum order 5000)	English Spanish	Z498 Z499	2 x 8	
Ad Slicks Camera-ready ads in a variety of sizes featuring older women. Includes slogan with Medicare information	English	C135		
Mammogram Reminder Pad A pad for clinicians with fifty tear-off fact sheets on mammograms to give to patients. Includes NCI's screening recommendations, Medicare mammography coverage, and sticker for patients' calendars reminding them of their appointment.	English	Z448		
"Do it for yourself, Do it for your family" Asian American and Pacific Islander (AAPI) women have the lowest mammography screening rattes of major ethnic groups in the U.S. Breast cancer is the most common type of cancer for Chinese women, the second most common for Vietnamese women, and the leading cause of death for Filipina women living in the U.S. These brochures are written in three Asican languages and in English to inform AAPI women about the benefits of mammography, NCI screening recommendations and Medicare coverage.	English Chinese Vietnamese Tagalog	P048 P082 P089 P141		

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